

# In it together

The impact of hearing loss on personal relationships

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Changing the world for deaf and hard of hearing people

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### Summary



Hearing loss is typically considered at an individual level. Processes such as diagnosis of hearing loss and fitting of hearing aids deal with the person concerned, with limited consideration of those around them. However, the experience of hearing loss is typically shared with – and managed by – both the person with hearing loss and their partner or family.

RNID conducted 23 interviews with people with hearing loss and their partners to gain a better understanding of how partners and families respond to hearing loss.

#### **Reactions to hearing loss**

- Partners played an instrumental role in making people aware of their hearing loss.
- Partners expected the person with hearing loss to take steps to minimise its impact, namely to demonstrate a degree of acceptance of their hearing loss and to wear their hearing aids.
- Partners took basic steps to communicate more effectively with the person with hearing loss and were a valuable source of support.

However, they found it difficult to understand the nature of hearing loss and how this was affected by factors such as tiredness and background noise.

- Partners tended to take one of two approaches to providing support. They would either work on acquiring hearing aids or equipment that could improve their partner's hearing loss or they would observe their partner, stepping in when they felt they were having difficulty hearing.
- Partners sometimes took steps to protect their partner's image with people they didn't know well, namely to ensure that they weren't perceived by others as rude.

#### Impact of hearing loss

- Hearing loss had a limited impact on the allocation of responsibilities, although in general the hearing partner did most telephoning work. In most cases neither partner resisted this; however, occasionally, hearing partners resisted taking this on where they were pushing for the person with hearing loss to retain as much independence as possible.
- Couples reported a change in the content and nature of communication, describing how those aspects of communication that are small but important, such as reflections on events, can be lost. In some cases, this led to a sense of isolation in both partners.
- Hearing loss caused frustration for both partners. In some circumstances, hearing loss led to couples talking at cross-purposes, causing friction which would sometimes spill over into ongoing resentment.
- Both participants with hearing loss and their partners reported feelings of loneliness. However, hearing partners, in particular, spoke of feeling lonely and felt that they were missing out on companionship.
- People with hearing loss and their partners had curtailed social activities. This illustrates how the couple, not just the individual with hearing loss, can withdraw from social interaction. This also suggests that couples can become lonely despite the partners interacting with each other.
- Participants reported mixed experiences of how their children adjusted to their hearing loss.

#### **Recommendations**

As a result of this research, **RNID** will be producing guidance for family members on hearing loss. We urge health and social care professionals, as well as service providers, to adopt and promote best practice when dealing with people who are hard of hearing and their families.

Audiologists and health care professionals should encourage partners or other family members to attend appointments so as to generate shared understanding of hearing loss and its effects.

**Social care staff** should likewise encourage family members to be present at assessments so as to enable partners or family members to adjust to hearing loss.

**Organisations** of and for older people and families should understand the dynamics of hearing loss and take them into account when planning and delivering services.

**Services and businesses** should ensure that their services are fully accessible to people who are hard of hearing, by fitting and maintaining loop systems and training staff in deaf awareness. A business that is closed to people who are hard of hearing may well be closed to their family, too.

### Introduction



Partners can play an instrumental role in making people aware of their hearing loss. They are also an important source of support despite sometimes finding it difficult to make the necessary sustained adjustments to hearing loss. In turn, hearing loss has an impact on relationships, changing the content and nature of communication with partners. Frustrations can arise and hearing loss has an impact on the activities, such as social events, that couples take part in.

#### Background

Hearing loss is typically considered at an individual level. Processes such as diagnosis of hearing loss and fitting of hearing aids deal with the person concerned, with limited consideration of those around them. However, it is essential to recognise that communication with other people lies at the heart of what RNID does and better communication is our ultimate goal. Moreover, the experience of hearing loss is typically shared with – and managed by – both the person with hearing loss and their partner or family.

This dynamic between the person with hearing loss and their family works in both directions. Research to date has suggested that family can make a person aware of their hearing loss and influence how they react to the hearing loss. In turn, a 2005 report suggests that where the person with hearing loss accepts this and takes responsibility for difficulties related to their hearing, they can benefit from happier relationships<sup>1</sup>.

Other studies have explored the impact of hearing loss and the fitting of hearing aids on couples and families. For instance, Brooks, Mellor and Hallam (2001) found that individuals with a hearing loss and their significant others experience similar amounts of difficulty in the areas of one-to-one conversation, group conversation and television viewing. More specifically, hearing loss can mean a decrease in intimate talk and joking with the family<sup>2</sup>.

<sup>&</sup>lt;sup>1</sup> Anderson, D.L. and Noble, W. 'Couples attributions about behaviours modulated by hearing impairment: Links with relationship satisfaction' *Int J Audiol.*, 2005 Apr;44(4): pp.197-205.

<sup>&</sup>lt;sup>2</sup> Brooks, D, Hallam, R and Mellor P. 'The effects on significant others of providing a hearing aid to the hearing-impaired partner', *British Journal of Audiology*, 2001, 35, pp.165-171.

Research has also explored reactions to partners' hearing loss. This suggests that an individual's partner's response to hearing loss influences how well the individual adjusts to hearing aids<sup>3</sup>. There has also been some comparison around gender; for instance, research found that females accommodate their male partner's hearing loss to a greater degree than males. The authors attribute this to female partners' commitment to maintaining communication within relationships, which means that they monitor their partner's behaviour to a greater extent<sup>4</sup>.

Finally, research has explored ways in which hearing partners respond to individuals' hearing loss. For instance, Hallberg and Barrenas (1993) categorise different strategies that female spouses use to deal with their husband's hearing loss as follows.

#### **Co-acting**

The spouse colludes with their husband to deny the impact of hearing loss on their lives.

#### Minimising

The spouse colludes with their husband to deny the impact of hearing loss on their lives but admits that the hearing loss has an impact to some degree.

#### Mediating

The spouse either controls the situation by listening very attentively, navigates their husband away from potential stressful situations and/or advises them privately how they should deal with their hearing loss.

#### Distancing

Partners end up living side by side and communication is barely existent<sup>5</sup>.

Despite these points, research to date has tended to focus on the person with hearing loss and hearing aids without taking account of the shared communication difficulties that hearing loss can cause. More specifically, while some research has identified the consequences of hearing loss for partners and families, some of the impact remains unexplored to date. However, it is important for us to understand the impact that hearing loss has on partners in order to better support them and because their experiences will, in turn, feed back into the experiences of the person with hearing loss.

#### **Research aims**

The aim of the research was to gain a better understanding of how partners and families respond to hearing loss.

More specifically, the research objectives were:

- to explore the role of the family in influencing people to go to their GP, their dealings with their GP and in the acquisition of hearing aids
- to capture how families adapt to hearing loss
- to explore the impact of an individual's hearing loss on their family
- to explore the impact of hearing loss on family dynamics.

<sup>&</sup>lt;sup>3</sup> Brooks, D N. 'The effect of attitude on benefit obtained from hearing aids', *British Journal of Audiology*, 1989, 23, pp.3-11. <sup>4</sup> Brooks, D N. 'The effect of attitude', pp. 3-11.

<sup>&</sup>lt;sup>5</sup> Hallberg, R M and Barrenas M, 'Living with a male with noise-induced hearing loss: experiences from the perspective of spouses', *British Journal of Audiology*, 1993, 27, pp.255-261.

#### Scope of the research

We interviewed families where at least one person has hearing loss. However, at the beginning of the research, we recognised that we can no longer assume that there is a typical family make-up. Therefore, in the context of this research, we defined family as people who live in the same household. In practice, all but one interview was conducted with a person with hearing loss and their partner. The remaining interview was with three participants; the person with hearing loss, her partner and her daughter. Therefore, the research findings are concerned with relationships with partners rather than wider families; however, in some cases, the findings and recommendations are relevant to the wider family.

Although we did not specify that those people with hearing loss should be hearing aid users, all but one of the participants with hearing loss had hearing aids. We have included quotes from participants in the report to illustrate the themes that emerge from the research. However, in order to maintain participants' anonymity we have not included their names. Instead, we have given details of the sex of each participant and their region. Where the report uses the term partner, this refers to the hearing partner.

The sections are as follows:

- 1. Partners' reaction to hearing loss.
- 2. The impact of hearing loss on people with hearing loss and their partners.
- 3. The dynamic within the wider family.
- 4. Some of the research participants' suggestions and advice around the issues in the report.



# Section 1: Partners' reaction to hearing loss

#### 1.1 Diagnosis

As found in previous research, families and, more specifically, partners played an instrumental role in making people aware of their hearing loss and in urging them to have this diagnosed. They also played a role in alerting them if there were any subsequent change in their hearing. This awareness did not always translate immediately into action on the part of the person with hearing loss. For instance, one participant described how his partner would push him to have a hearing test:

#### "And occasionally she would say 'you need your ears tested.""

(Male with hearing loss, South East)

However, in some cases, hearing partners did not notice hearing loss because they had automatically adjusted to this without being aware that they were doing so.

#### 1.2 Expectations

Partners and families were clear about their expectation and need for the person with hearing loss themselves to take steps to minimise the impact of their hearing loss. In the first place, partners expected the person with hearing loss to demonstrate a degree of acceptance of it as, without this acceptance, they were less likely to take steps to mitigate the impact. More specifically, they expected the person to wear their hearing aids and, to a lesser degree, to tell other people about their hearing loss. These expectations were slightly tempered by the understanding that hearing aids can be uncomfortable and that the partner may not feel happy telling people about their hearing loss.

#### "You won't accept you've got a hearing loss, that's the problem."

(Male partner, Wales)

#### "My main bugbear is that he just doesn't wear it [hearing aid]."

(Female partner, South West)

Frustration was caused by the extra effort required of the hearing partner in order to deal with situations where the partner with hearing loss was unwilling to take the steps outlined above. However, it also stemmed from the fact that the hearing partner proceeded with some communication on the basis that the person with hearing loss was wearing their hearing aid and could hear them – and this turned out not to be the case. In turn, this led to ineffective communication and related frustrations.

"If he's in the garden and I'm in the garden with him and maybe someone's mowing the lawn, he will be disturbed by that. He tends to take it [the hearing aid] out and then I won't notice and then we do have issues over that."

(Female partner, Midlands)

This also reflected difficulties experienced by hearing partners in assessing the impact of the hearing loss in different circumstances (explored in the next section).



Tellingly, these areas were where most differences of perception appeared within the interview. For instance, couples would have differing assessments of the willingness of the person with hearing loss to use their hearing aid.

#### "He doesn't persevere with it." "I do persevere."

(Female partner and male with hearing loss, South East)

This illustrates differing perceptions regarding the extent to which the person with hearing loss met their partner's expectations.

#### 1.3 Adjusting to hearing loss

Partners took basic steps such as speaking clearly and looking directly at their partner when speaking in order to communicate more effectively. While people with hearing loss occasionally recalled pointing out particular ways in which they should act, they generally did not recall how their partner knew what steps to take in order to adjust to their hearing loss.

Where participants reported that partners or other family members were unwilling to adjust, this tended to be because they did not have – or were unwilling to spend – time adapting to their partner's hearing loss.

For instance, a participant described her ex-partner's lack of adjustment:

"I always used to say to him '\_\_\_\_, if you want my attention just say \_\_\_\_\_. I will turn and look at you, focus my brain on you and then you can say....'. But he didn't have time for that."

(Female with hearing loss, South East)



#### Challenges

Partners characterised the challenges of minimising the impact of hearing loss as tricky. While all of the partners were willing to put time and effort, to varying degrees, into minimising the impact, they found some aspects of this process particularly challenging.

Partners found it difficult to understand the nature of hearing loss and how this was affected by changes in internal and external factors. Both the people with hearing loss and the partners described this challenge:

"With hearing loss it depends on how tired you are, how much you have to concentrate. How well you hear depends on the background noise, on the timbre and pitch of people's voices and so it's difficult for somebody who doesn't have hearing loss to understand how all those factors come into play."

(Female with hearing loss, South East)

#### "I'll say 'did you hear that?' and he'll say 'no'. I say, 'I don't know what you do hear."

(Female partner, Midlands)

Partners typically understood the impact of background noise on the person's ability to hear; however, they were less likely to recognise the impact of tiredness. This lack of understanding occasionally led to conflict where the hearing partner felt that they were speaking clearly and at the right volume whereas their spouse felt, for instance, that they were shouting. Difficulty understanding the nature of hearing loss also caused frustration where, for instance, the partner was asked to repeat something and they repeated the wrong part of the sentence. Hearing aids could also act as a complicating factor in this respect, particularly when an individual first acquired a hearing aid and their partner was required to adjust to their new level of hearing.

#### "So you know it's difficult to get it right, whether you're speaking very loudly or too quietly."

(Female partner, Wales)

Partners and families also described how they simply forget, despite their best intentions, to take the steps to enable their partner to hear them, particularly within the home. For instance, they described how they would shout to their partner from another room. This could lead to slower, less effective communication as well as frustrations and misunderstanding.

#### "I am not blaming you that you can't hear, I am saying it's my fault because I do tend to forget, because he is very good with his hearing aids, and I do tend to forget that he is deaf."

(Female partner, Midlands)

Hearing partners typically saw it as their responsibility to take steps such as looking directly as the person with hearing loss when speaking. However, exceptionally, hearing partners felt that they were only talking naturally, that they couldn't be expected to change and that it was up to the person with hearing loss to accept that they could not hear.

"If you've got somebody who won't accept that they can't hear something, which is the scenario, automatically you are going to have friction at all times, because you are just doing something naturally: 'I am down here, oh look at this', and you're not going to hear it."

(Male partner, Wales)

It is important to recognise that these difficulties were viewed by participants as frustrations that are possible to live with. People with hearing loss were more likely to experience difficulties communicating with people other than their partner.

Interestingly, it was very unusual for the hearing partner or family to take part in activities independently where they had not done so before their partner started to lose their hearing.

#### 1.4 Providing support

#### **Technology versus observation**

Partners tended to take one of two approaches to hearing loss. They would either work on acquiring hearing aids or equipment that could improve their partner's hearing loss or they would observe their partner, stepping in when they felt that they were having difficulty hearing.

Broadly speaking, partners took one or the other approach (though, exceptionally, partners did not describe taking either approach) and male partners were more likely to take the first approach while female partners were more likely to take the second. This finding accords with previous research that suggests that females monitor their partner's behaviour to a greater extent than males. The two approaches are described:

#### Technology

In these cases, partners invested effort in creating the conditions where the person could hear more easily. Their focus was the science of sound and of hearing. They would typically research hearing aids and assess those that worked best for their partner as well as researching and installing equipment.

"Go back before \_\_\_\_\_ had digital hearing aids, which is only two years ago, I did arrange to have an extension loudspeaker from the TV set to her armchair."

(Male partner, South East)

"When he [hearing aid specialist] comes here I always try to be here so that if there is any confusion, if \_\_\_\_\_ doesn't understand something....I will ask for her."

(Male partner, South East)

The partners typically described this as an extension of their interest or belief in the value of technology.

#### Observation

In these cases, partners observed their spouse and usually stepped in when they did not hear a third party or, for example, the television. Their focus was the quality of communication and the impact of hearing loss on relationships – both their own relationship and their partner's relationship with other family members and friends.

"I sort of channel in, which is something that I didn't do very much before, so that changed. I began to become more alert that there might be a problem."

(Female partner, South East)



"Particularly in social situations, she's very attuned to whether I'm struggling or not, whether I'm missing important things and she will say, 'did you catch that?"

(Female partner, South East)

Couples who had met when their partner already had some hearing loss were also more likely to take this approach.

#### **Mediating communication**

Unsurprisingly, those hearing partners who took the above approach were also more likely to notice any change in their partner's communication with other people and to take steps to mediate their communication with them. For instance, hearing partners described how their partner's position had changed within the wider family.

"If we had a family gathering of any kind, whereas grandad was once always in the middle of it, now he doesn't seem to be so much because he's not hearing what people are saying."

(Female partner, South West)

They took steps to facilitate their partner's communication with other people, to protect their feelings and to make them more involved in social and family life. For instance, they were more alert when conversations were taking place to ensure that no communication was missed, often updating their partners later.

#### "I would be listening very hard in case \_\_\_\_\_ did not hear something."

(Female partner, South East)

#### "And what I miss, she'll tell me when I get home."

(Male with hearing loss, North West)

Hearing partners also urged their partners to tell people that they had a hearing loss. Alternately, the partners themselves reminded other people about the hearing loss and how they should or should not react. For instance, when siblings were making fun of a participant's hearing loss, his wife intervened:

#### "I talked to them about it and said 'back off, that hurts, he's getting upset'."

(Female partner, South East)

Another participant described reminding her grandchildren about her partner's hearing loss:

#### "Occasionally you have to say to one of the children 'say that again but make sure that grandad hears you'."

(Female partner, South West)

Furthermore, hearing partners took steps to protect their partner's image with people that they didn't know well – namely, to ensure that they weren't perceived by other people as rude. For instance, they would make other people aware of their partner's hearing loss or take steps such as answering someone where the communication is unimportant and the question is addressed to both people within the couple (for instance, at a supermarket checkout).

"I'm often aware that maybe the checkout girl will say something and \_\_\_\_\_ hasn't heard and not responded and, if I don't respond, they might think 'ignorant person' by not being aware."

(Male partner, Midlands)

"I've said to them straight away because I don't want people noticing before I say to them; I don't want them thinking she is ignorant."

(Male partner, Scotland)

It may be that, by protecting their partner's image, people are protecting the image of the couple and, by extension, their own image within the partnership.



#### **Telling people**

Hearing partners took different positions on whether they would tell others about their partner's hearing loss. While some would tell people outright with no reflection, others were more hesitant, mainly because their partner themselves would not wish them to tell people indiscriminately. A partner described the different approaches to this:

"Someone else might want that if you go into a room, the first thing you say to everybody is 'hi I'm \_\_\_\_, this is \_\_\_\_\_ is deaf by the way' whereas others would absolutely cringe. I know where I'd be if I did it – I'd be in A & E!"

(Male partner, South West)

Some partners took a more assertive approach than this; where their partners were unwilling to tell people about their hearing loss, they would try and persuade them that they should.

The timing of telling people occasionally presented a dilemma to partners or family where they had to decide whether to tell their friends about their partner's hearing loss or leave them to realise that they had hearing loss.

For instance, the daughter of someone with hearing loss said:

#### "As an adult now, bringing people home, do you highlight it or do you just wait and deal with a problem if it arises?"

(Family member, Midlands)

Another partner described how he would tell people before they noticed:

"I've got to know them really well so, next time in their company I've said to them straight away, because I don't want people noticing before I say anything. I don't want them thinking she is ignorant."

(Female with hearing loss, Scotland)

Here the risks of not telling people are that the person with hearing loss would eventually be excluded or judged to be rude. In these cases, the partner or family, along with the person with hearing loss, weighed up whether the third party was likely to be someone that they would see regularly. If this were so, they were more likely to tell them about the hearing loss.

#### Positioning

Partners and families positioned themselves to enable the person with hearing loss to hear them better in the following ways:

- moving into their line of vision
- changing sides when walking/sitting so that they were sat on the side on which the person had better hearing
- avoiding noisy areas in public places.

The person with hearing loss also took steps to position themselves so that they could hear. For example, one participant described how, at family gatherings, he would ensure that he sat at the corner of the table so he could see all family members.

Exceptionally, families would invert this rule; for instance, a husband described how he would sit on the side on which his wife's hearing was worse so that if other people spoke to her from that side, he could alert her.



#### 1.5 Discussion

The research shows that partners and families find it difficult to understand the nature of hearing loss. Additionally, different factors, such as tiredness and background noise, will have an impact on this. Moreover, families may not realise how tiring it is for someone with hearing loss to focus for long periods of time. There may be scope for organisations to provide advice and resources for families in order to help them understand how it feels for someone to have hearing loss and, specifically, why they may not be able to hear in some situations while they can in others. The idea of family group sessions was suggested by some participants and is discussed later in this report.

This research demonstrates that there are different ways of providing support to a person with hearing loss. While all the participants were grateful for support given, the type of approach taken appeared to reflect the preferences of the partner offering support at least as much as it reflected the needs of the person with hearing loss.

Where participants reported that partners or families were unwilling to take steps in order to adjust to their hearing loss, this was related to lack of time. In these cases, the person who did not have (or was unwilling to) make the time was of working age. Such adjustments can take more time; for instance, repeating yourself, checking that the person with hearing loss has heard, moving into the person's line of vision. However, many people are retired by the time their partner has significant hearing loss and, therefore, they may well have more time to offer them.

# Section 2 : The impact of hearing loss

#### 2.1 On the person with hearing loss

Hearing partners could play a positive role both in providing practical assistance (such as answering the telephone) and providing advice on equipment. Partners could also give the person with hearing loss more confidence and enable them to feel at ease.

"For me it's about having the confidence just to be there because they know that if I'm not responding it's because I can't hear, not because I don't want to take part or because I'm being ignorant or any of those things."

(Female with hearing loss, Midlands)

"Because I've got \_\_\_\_ I am very lucky – if I were on my own, I think that would be a struggle... I might get a bit more introverted."

(Female with hearing loss, Wales)

The confidence came from the fact that the hearing partner had an understanding of why they acted in the way that they did. In these cases, they could feel at ease because their actions would not be interpreted as standoffish or rude. Similarly, some partners would push the person with hearing loss to be more sociable.

"You really ought to take a leaf out of your mother's book because she hasn't given up on her social life at all..... and she does have problems hearing."

(Female partner, South East)

#### 2.2 On the partner

#### **Spending time**

Some hearing partners reported that they had stopped doing particular things because of their partner's hearing loss; namely, listening to music and, occasionally, watching television.

"I've stopped listening to music because \_\_\_\_\_ has. Basically, because if I do, he just moans beside me that he can't hear it."

(Female partner, South East)

"I sit and watch television with \_\_\_\_\_ I don't bother with it.... I do the crossword. You know, I can't sit and watch signing (subtitles) but it really gets him down."

(Female partner, Midlands)

#### **Worries**

Hearing partners and family members also reported worries related to hearing loss. This was often related to the fact that they had had to alert their partner to something because they had not heard it; they subsequently worried about what would happen when they weren't there.

"Here at home, I think the one thing that does worry me is the fire alarm in the night. If it went off, and he was in bed, he wouldn't hear it, and that did worry me when I was in the hospital."

(Female partner, Midlands)

"I worry just about the fact that any little accident can happen without your full hearing – even along the towpath, I worry that he would not hear another bike coming behind him and that sort of thing."

(Female partner, Midlands)

Specific worries that partners identified were around the following:

- not hearing the smoke alarm
- not hearing the doorbell
- not hearing traffic when walking in the road
- partner with hearing loss withdrawing from communication with wider family
- · accidents when out cycling
- not hearing the indicators when driving and, therefore, forgetting to turn them off.



#### 2.3 On the relationship

# Allocation of responsibilities within the relationship

Hearing loss had a limited impact on the allocation of responsibilities. Generally, it meant that the hearing partner did most telephoning work – for instance, calling the bank. Other situations where the partner would take responsibility were during casual interaction with other people, such as when speaking to staff in a café or a supermarket.

In most cases, neither partner resisted the transfer of this responsibility. Exceptions to this were where the hearing partner felt that this caring attitude was not being reciprocated or where they wanted the person with hearing loss to retain some independence. For instance, a partner explained her feelings regarding the new responsibility and the fact that her arthritis had not resulted in her partner taking on additional responsibilities. In this way, she felt that her actions were not reciprocated.

#### "I do sometimes feel a bit cheesed off about it because the fact that I've got arthritis hasn't made \_\_\_\_\_ do all the shopping."

#### (Female partner, South East)

This can be contrasted with a situation where there was some reciprocity in terms of taking on responsibilities and both partners were happy with the status quo.

"If there's a letter to be written I don't mind. I quite enjoy it and I do feel that's my job because \_\_\_\_\_ does the phone work."

#### "It's her area of expertise."

(Female with hearing loss and female partner, South East)

Hearing partners also resisted taking on this responsibility where they were pushing for the person with hearing loss to retain as much independence as possible. In these cases, they described their aims as altruistic in that they felt that the person with hearing loss would benefit by retaining such responsibilities. Their key concern was to retain the sphere in which their partner could remain independent and to limit their withdrawal from interaction with other people.

"When we go out to restaurants, the theatre or anywhere like that..... actually make the effort, don't just not converse, try and talk to people – I think it's better if you can rather than just withdraw."

(Female partner, Midlands)

Previous research has drawn attention to the risk of development of a relationship of dependency where a hearing partner monitored their partner's communication. However, in this research, there was clear evidence that some hearing partners were aware of this risk and took steps to avoid their partner becoming overly-dependent on them. This may be important in terms of long-term outcomes where people with hearing loss may lose their partner and can no longer depend on them. The person with hearing loss may benefit at this stage where their partner has encouraged them to remain more independent.

#### **Content of communication**

Some couples explicitly described changes in the content and nature of communication. The sense of loss experienced in these cases provides us with some insight into the role of verbal communication within their relationships. In particular, communication that seems important on the surface, such as the communication of factual information or arrangements, is not necessarily the most important information. Similarly, small superficial communications can add up to something much more significant in the context of a relationship and it is difficult to judge the types of communication that are important.

Participants' reflections illustrated how those aspects of communication that are small but important can be lost:

#### "They're the sort of areas that are quite small but quite significant."

(Male partner, South East)

#### "Small asides count for so much, it breaks my heart and breaks her heart that these little things can't be shared."

(Male with hearing loss, South East)

There was the sense that these small communications added up to something much greater within relationships, feeding into a sense of companionship or a shared reflection on events. Particular areas such as asides or comments on a television or radio programme were most likely to be sacrificed.

Other areas that were more likely to be lost were jokes and humour. Participants also experienced more difficulty communicating in the morning before hearing aids were worn; a time that was seen by some participants as quite intimate. In some cases this led to a sense of isolation in both partners; however, a sense of loneliness was expressed more frequently by the hearing partners than the people with hearing loss themselves. Participants also referred to a sense of a loss of companionship. However, partners occasionally minimised this sense of loss by putting their experience in the context of a long or successful relationship or by pointing out that they tended to know what their partner was going to say.

Attempts at communication in particular areas, such as jokes, could also lead to frustrations for both partners and, occasionally, a sense of being dismissed on the part of the person with hearing loss. For instance, partners described how they can try and tell a joke or make a humorous comment but their partner doesn't hear and then they don't want to repeat it because, from their point of view, it's something that doesn't bear repetition.

"You can go through the motions but if I say, forget it, that's obviously going to annoy \_\_\_\_\_. But at the same time, there's no pleasure in telling someone, it's quite trivial'

(Male partner, South East)

Unsurprisingly, individuals with hearing loss felt excluded or dismissed if they were not included in jokes.

#### Amount of communication

Participants also expressed the view that difficulties around communication mean that the amount of communication has decreased.

#### "I think in many ways I just don't bother an awful lot of the time. You just use minimum words again because it's easier that way."

(Female partner, South East)

As mentioned above, problems caused by this type of experience were characterised as sources of frustration and upset within the relationship; however, they were seen as something that participants could learn to live with.

#### **Frustration**

Unsurprisingly, hearing loss caused frustration for both partners. Typical situations included hearing partners looking away while speaking or speaking too loudly. On the other hand, hearing partners themselves experienced frustration at having to repeat themselves or not being able to make themselves understood.

More seriously, in some circumstances, hearing loss had led to couples talking at cross-purposes, causing friction which, in some cases, would spill over into ongoing resentment.

A hearing partner made the point to a participant with hearing loss:

"I am saying that will cause a misinterpretation at that point because you have heard something different in your own mind. What can be a constructive comment can be actually heard as a misconstrued comment.....there's reaction to

# something where there wasn't an intention to cause a reaction."

(Male partner, Wales)

#### Loneliness

Both participants with hearing loss and hearing participants reported feelings of loneliness.

However, hearing partners, in particular, spoke of feeling lonely and that they were missing out on companionship. It was striking that they felt this despite the fact that they were often in longstanding partnerships and spent significant time with their partner.

# "It can be lonely if someone doesn't hear you but you can hear them."

(Female partner, Wales)

#### "You say it depresses you and makes you lonely sometimes."

(Male with hearing loss, South East)

#### **Activities**

Participants had made some changes to the social activities that they participated in.

To some degree they had curtailed activities – for instance, they might no longer go to big group events. Partners would typically stick together; if the person with hearing loss did not feel able to attend a social event, then the other person did not attend either. Generally, both parties were accepting of this and did not express it as a big loss. However, participants occasionally expressed a sense of loss or frustration with this situation.

For instance, a hearing partner described evenings when they go on holiday:

"We don't speak to almost anyone, only at the tables and evening meals, and sometimes I wonder why I bother to go."

(Female partner, Midlands)

Another hearing partner described the limitations that he ascribed to his partner's hearing loss:

"It prevents you doing things together. Whereas before you could go to anything together, you now can't, so if you want to go to the cinema you only go to musicals, you go the theatre when the subtitles are on....it's socially debilitating when you are together."

(Male partner, Wales)



This illustrates how the couple, not just the individual with hearing loss, can withdraw from social interaction and suggests that couples can become lonely despite the partners interacting with each other.

Unsurprisingly, participants were more likely to stay in contact with other family members than other people and to continue to participate in family events.

Often participants would continue to participate in activities but would make adjustments to make it easier for them to participate. For instance, one participant described how he would read a play before going to the theatre to make it more likely that he would understand what was happening and to enable him and his wife to continue a shared activity.

Similarly, participants would avoid noisy restaurants or would invite friends over rather than meeting them in a noisy pub. In this way, they would continue to gain the central benefit of the activity.

There was some suggestion that those participants with hearing loss tended to spend more time with the circle of people that they already knew and made fewer new acquaintances than previously. As in most cases, hearing partners took part in the same activities which meant that they also made fewer new acquaintances. One partner suggested that this was because his wife had got used to the voices of her circle of friends and acquaintances and it would be difficult to get used to a new circle.

"I think the answer is you have your circle and, providing you can manage with that, the problem is introducing a new circle, because you don't know what the voices are like."

#### 2.4 Discussion

Both the participants with or without hearing loss reported that it had an adverse impact on communication and also on the activities that they undertook together. However, this research did not identify evidence that hearing loss itself leads to relationship breakdown. Previous research has also found that hearing loss is not directly associated with relationship breakdown (Anderson and Noble, 2005).

Occasionally, participants had made different types of adjustments, such as reading a play before going to the theatre in order to compensate to some degree for anything they missed, enabling discussion with their partner about the play afterwards.

The type of adjustment is individual, depending on a couple's interests and what matters to them. Moreover, it requires a tacit or explicit understanding as to what activities are important in the context of a relationship and can also require a degree of commitment.

Some of the experiences described during the research demonstrated the challenges faced when designing technology for people with hearing loss. Activities such as watching television are often shared with other family members; however, those family members may find subtitling off-putting and, where a loop is used, the person with hearing loss cannot watch television and speak to their family. In this way, a big challenge is designing technology that reflects the way people live.

Partners described anxiety around the safety of the participants with hearing loss. In some cases, there is equipment available that can at least partly assuage those concerns, such as fire alarms with a strobe light. This demonstrates how RNID still needs to work to make people aware of such equipment.

(Male partner, Wales)

# Section 3 : The dynamic within the wider family

#### 3.1 Household structure

Participants typically lived in a two-person household consisting of the person with hearing loss and their partner. Unsurprisingly, where they compared this with previous experiences where they were part of a larger household, they found it easier to manage in their current arrangement.

#### "It's easier now because there's just \_\_\_\_\_ and me here, all the children have fled the nest."

(Female with hearing loss, Midlands)

#### 3.2 Children

Participants reported mixed experiences of how their children adjusted to their hearing loss. While participants reported that their children took steps to minimise the impact of their hearing loss, some also found that children would adjust for a period of time and then forget.

#### "You make your protest and say "I'm deaf, you'll have to do this' and they do it for about five minutes and then they drift back to ordinary conversation terms and behaviour."

(Male with hearing loss, South East)

Another reported that her son spoke very fast and, when she asked him to slow down, this would tend to make him not talk at all. It may be more difficult for people who are not in the same household to remember to make the necessary adjustments. This is because they don't have to make these on a sustained basis, meaning that it is less likely to become second nature.

#### 3.3 Grandchildren

Participants generally reported that their grandchildren were receptive to making changes in order to accommodate their hearing loss.

"The [grand]children were very good because once they'd been told, in fact they would probably be better than my daughter. They think this is great, this is something I can do, I can be really helpful."

(Female with hearing loss, Wales)

"He's always known you've 'got something the matter with your ears'......he's always stood in front of you, hasn't he? He knows."

(Female partner, Wales)

To some degree, accounts of how well grandchildren adjusted to hearing loss compared favourably to those around children. Where participants experienced difficulty communicating with grandchildren, this tended to be related to the pitch of their voices and the fact that they tended to see them within a larger family group.

#### 3.4 Discussion

To some degree, accounts of how well grandchildren adjusted to hearing loss compared favourably to those around children. However, this may be related to participants' expectations regarding children's and grandchildren's respective behaviour. There was also a recognition and appreciation of the role that their children had played in influencing the grandchildren to adapt to the person with hearing loss.

# Section 4 : Specific suggestions

Some participants made specific suggestions as to useful steps for people with hearing loss and their partners or families.

- The partner should find out exactly what the person with hearing loss needs, and is comfortable with, in terms of support.
- Audiologists should encourage the family to attend an appointment alongside the person with hearing loss. This would help hearing partners to understand the nature of hearing loss and what the person with hearing loss could and could not hear.
- The introduction of volunteers who could visit people at home and talk to their families in order to explain the techniques that they could use to help the person with hearing loss.
- Discussion groups that couples could attend in order to deal with issues arising from hearing loss. This would reassure the couple that other people faced the same issues.

#### 4.1 Discussion

Some audiology departments tell their patients that they can bring a family member with them; however, this is not consistently the case. It would be helpful if audiologists could systematically encourage patients to bring along a family member or friend in their appointment letter. This would make patients who wanted to bring a family member feel that they could. Moreover, it would suggest to other patients that this could be of benefit to them.

Some of the challenges faced by people with hearing loss and, in particular, their partners are those typically addressed with a hearing therapist.

A hearing therapist works out a programme for a person with hearing loss and, in some cases, their families, to improve their communication skills. They cover areas such as help with hearing aids, counselling people with hearing loss and equipment available. Some participants felt that this type of service would help the hearing partner to understand what the person with hearing loss was experiencing. Similarly, some participants felt that they could benefit from group work with other couples to help them realise that any difficulties that they were experiencing were widespread and to discuss strategies with other couples.

While there are currently fewer hearing therapists, this type of support is being delivered via other routes; for instance, RNID's Hear to Help projects sometimes provide advice for family members. It would be useful to measure the extent of demand for this type of support and, if there is unmet demand, to look into the role that RNID can play in providing this type of support.

# Section 5 : Conclusions and recommendations

#### 5.1 Reaction to hearing loss

As found in previous research, partners played an instrumental role in making people aware of their hearing loss. While some of the four million people with undiagnosed hearing loss live alone, partners potentially provide a way in for RNID to address the hearing loss for the remaining group.

Partners reported difficulties understanding the nature of hearing loss and, while they were willing to take the steps to enable their partner to hear them, they sometimes forgot to make the necessary sustained adjustments.

Partners tended to take one of two approaches to providing support; either investing effort in creating the conditions so that the person with hearing loss could hear more easily or stepping in when their partner did not hear a third party. Hearing partners who took the second approach were more likely to take steps to mediate their partner's communication with third parties.

These findings demonstrate that other household members play an important role in providing support to people with hearing loss. This, along with previous research findings, suggests that attention should be paid to single person households where people with hearing loss do not benefit from the support of other household members.



#### 5.2 Impact of hearing loss

Hearing loss had a limited impact on the allocation of responsibilities within relationships, generally meaning that the hearing partner did most telephoning work. Typically, neither partner resisted this transfer, except where the hearing partner wanted the person with hearing loss to retain some independence. This demonstrates how partners can play a role in fostering independence on the part of the person with hearing loss.

Some couples explicitly described changes in the content and nature of communication. Particular areas such as asides or comments on a television or radio programme were most likely to be sacrificed. There was the sense that these small communications added up to something much greater within relationships, feeding into a sense of companionship and shared reflection on external events. Therefore, couples experienced any hindrance to this communication as a loss and, in some cases, this led to a sense of isolation on the part of both partners. Any adjustments that couples make are very individual, depending on their interests and what matters to them.

Unsurprisingly, hearing loss caused frustrations for both partners in situations such as hearing partners looking away while speaking or speaking too loudly.

Participants had made some changes to activities – for instance, curtailing particular social activities. Unsurprisingly, partners would typically stick together. Some partners reported that they had stopped doing particular things because of their partner's hearing, namely listening to music at home.

Hearing partners and other family members reported worries around hearing loss and safety and, in particular, family members worried about what might happen when they weren't there.

Participants reported mixed experiences of how their children adjusted to their hearing loss. However, they generally reported that their grandchildren were very receptive to making changes.

#### **Recommendations**

As a result of this research, **RNID** will be producing guidance for family members on hearing loss. We urge health and social care professionals, as well as service providers, to adopt and promote best practice when dealing with people who are hard of hearing and their families.

Audiologists and health care professionals should encourage partners or other family members to attend appointments so as to generate shared understanding of hearing loss and its effects.

**Social care staff** should likewise encourage family members to be present at assessments so as to enable partners or family members to adjust to hearing loss.

**Organisations** of and for older people and families should understand the dynamics of hearing loss and take them into account when planning and delivering services.

**Services and businesses** should ensure that their services are fully accessible to people who are hard of hearing, by fitting and maintaining loop systems and training staff in deaf awareness. A business that is closed to people who are hard of hearing may well be closed to their family, too.

# Methodology

This research adopted a wholly qualitative methodology of face-to-face interviews. Qualitative methods are ideal for exploring people's experiences and the meanings that these experiences hold for them.

Social research is either quantitative or qualitative. Quantitative research typically takes the form of a survey and is used to measure experiences and beliefs, producing numerical data. Qualitative research typically takes the form of in-depth interviews or focus groups and is used to gain an insight into people's lives and the processes that inform their behaviours and experiences. We selected a qualitative methodology for this research in order to explore how families adjust to hearing loss and the impact of hearing loss on them. These findings would not have been so accessible using a quantitative methodology. However, while this type of qualitative research enables us to identify the range of people's experiences, it does not look to produce statistics.

#### **Recruitment of participants**

The interviews took place in a variety of urban and rural locations. We included an advertisement for participants in the RNID membership magazine, *One in Seven*, and in the RNID members' email. We also advertised for participants in the local regional press.

#### The interviews

Twenty-three interviews took place between September and December 2009. The interviews were conducted by two members of the Social Research and Policy team. The breakdown of participants was as follows:

- nine couples where a female partner had hearing loss and a male partner did not have hearing loss
- one couple where a female partner had hearing loss and a female partner did not have hearing loss
- one couple where a female partner had hearing loss and a male partner and daughter did not have hearing loss
- 11 couples where a male partner had hearing loss and a female partner did not have hearing loss
- one couple where both partners had hearing loss.

The majority of participants with hearing loss wore hearing aids.

The interviews took place in either the participants' homes or in an RNID office. The interviews lasted between 30 and 70 minutes each. We recorded the interviews, as agreed by the participants.

#### Analysing and interpreting the findings

Written transcriptions of the data from the interviews were undertaken to provide a full anonymised record of each interview, and a summary of the remaining interview. Each of these transcripts was then coded in terms of emerging themes. This report outlines findings from the information provided by the people who chose to take part in this study. We have drawn out themes on the basis of what the participants said and remembered during the interviews.

We have included quotations in the report in order to illustrate some of the themes which emerged. These quotations are taken directly from the verbatim transcripts of the research. All the quotations are anonymous. We're RNID, the charity working to create a world where deafness or hearing loss do not limit or determine opportunity, and where people value their hearing.

There are a number of ways to support us. To find out more:

Go to

#### www.rnid.org.uk

Contact our Information Line

#### Telephone 0808 808 0123 Textphone 0808 808 9000

Or write to us informationline@rnid.org.uk

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